

Abstract

The Massachusetts Executive Office of Elder Affairs (Elder Affairs), in partnership with Massachusetts Rehabilitation Commission (MRC), the Massachusetts Executive Office of Health and Human Services Office of Disability Policies and Programs (ODPP), the Massachusetts Department of Mental Health (DMH), and Aging and Disability Resource Consortia (ADRC) partners statewide is seeking to enhance the Massachusetts ADRC Options Counseling Program by strengthening and refining its current standards to ensure that all options counselors throughout Massachusetts have the capacity to serve people with disabilities, including mental health and cognitive disabilities, and to make information on consumer directed services available to all Options Counseling consumers.

This goal will be achieved through the following objectives: 1) Develop training to expand the ability of Options Counseling staff to serve people with disabilities, including mental health and cognitive disabilities, and to ensure that Options Counseling incorporates consumer direction, choice and dignity of risk; 2) Acquire a comprehensive consumer database or interface to track Options Counseling services statewide and to facilitate referrals between ADRC partners; 3) Review, and revise if necessary, current state standards for Options Counseling; 4) Monitor delivery and impact of Options Counseling; 5) Work with the Administration on Aging (AoA) and other grantees to develop national Options Counseling standards.

Outcomes will include 1) Improved capacity to facilitate consumer direction and serve people with a range of disabilities; 2) Improved capacity to track referrals and outcomes of Options Counseling program; 3) More efficient system of referrals among ADRC partners; and 4) A set of enhanced state standards that will inform development of national Options Counseling Standards.

Current Status

Options Counseling was launched in Massachusetts in June 2008 as a core service of its three pilot ADRCs: Metrowest, Merrimack Valley, and Greater North Shore. In Massachusetts, ADRCs are partnerships between Aging Service Access Points/Area Agencies on Aging (ASAPs/AAAs), which serve adults age 60 and over, and Independent Living Centers (ILCs), which serve people with disabilities of all ages. ADRCs provide a network of information, referral and assistance to elders and people with disabilities to help them remain independent and engaged in their communities for as long as possible.

The goal of Options Counseling is to assist individuals to make informed choices about setting, services and financial resources that best meet their long term support needs. The Massachusetts model is responsive to a state mandate that specifies the provision of pre-admission counseling prior to nursing facility admission. The Massachusetts ADRC Options Counseling program moves beyond the statute by ensuring that elders and people with disabilities are provided with information about long term support options and decision support throughout their planning process, not only prior to nursing facility admission.

To support data collection related to the program, databases used by the ADRC partners—Social Assistance Management System (SAMS), which is used by the ASAPs, and Independent Living Data Management System (IDMS), which is used by the ILCs—have been modified to allow counselors to capture key elements of the counseling sessions, including goals and outcomes, which help identify nursing facility diversions; the number and type of sessions, to estimate the cost of services; and outreach and community education to expand the reach of Options Counseling. Each month, data is collected and reviewed from each ADRC by Elder Affairs and MRC.

Training Needs. Options counselors at the three pilot sites identified a need for more training in the areas of consumer direction and serving people with mental health and cognitive disabilities. Mental health is a growing area of concern, as older adults experience high rates of depression, anxiety and behavioral issues associated with chronic illnesses, particularly Alzheimer's disease, and other cognitive impairments. Among younger people with disabilities, many have mental health disabilities as their primary or secondary disability. Over 20 percent of Massachusetts residents with disabilities report experiencing poor mental health for fifteen or more days per month, as compared with 4.7 percent for people with no disabilities.¹

As ADRCs are reaching out to more diverse constituencies, including people with mental health and cognitive disabilities, ADRC staff report a need for a greater level of understanding among options counselors of people with disabilities and the services available for them.

IT Needs. Implementation of a robust, coordinated and streamlined consumer database across the ADRC network to track consumer data for Options Counseling has remained a challenge throughout ADRC project development. Currently, Elder Affairs and MRC IT staff are working with representatives from the ADRC pilot sites and the MRC to

¹ <http://www.mass.gov/Eoohs2/docs/dph/masschip/disability/disabilitymassstate.rtf>

define what data needs to be collected on Options Counseling consumers, how to collect it and how it is to be reported. Funding from an AoA Community Living Program grant is supporting training costs for ADRC staff in the area of documentation and reporting, ensuring that staff at both ASAPs and ILCs enter data that holds the same definitions and parameters for each agency, so that data can be combined for reporting, and to ensure overall accuracy. Fundamental limitations in SAMS and IDMS prevent significant changes beyond these improvements.

Overall Approach

Elder Affairs, in partnership with MRC, ODPP, DMH and ADRC partners statewide propose improving statewide Options Counseling standards by broadening the program's impact and reach. The program's capacity to track services and referrals, and to serve people with disabilities, including mental health and cognitive disabilities will be enhanced by the development and implementation of expanded standards.

Training

Elder Affairs and MRC will work with ADRC partner agencies to develop specialized trainings for options counselors in consumer direction and serving consumers with mental health and cognitive disabilities. This team will schedule a minimum of three regional trainings for both categories, as well as one webinar on mental health and cognitive disabilities.

1) Consumer Direction. Elder Affairs and MRC will work with the ILCs and other ADRC partners to develop a training to help options counselors to understand the history, philosophy and the practical applications of consumer directed approaches so that they can incorporate this into the guidance and content of the counseling session. The training will also cover the resources, programs and services available to consumers in the community which support consumer control, and will draw on an array of training materials and resources used by aging and disability network agencies.

2) Mental Health and Cognitive Disabilities. Trainings on mental health and cognitive disabilities will be developed and conducted by qualified mental health professionals with the assistance of staff from DMH's central office as well as their three area offices, which have a fully developed curriculum and regularly offer trainings to health and human services providers. Members of the local mental health disability community, such as Recovery Learning Communities and DMH site offices, as well as the Disability Law Center (one of our state's protection and advocacy

providers), will also be involved in the development of the trainings, as will members of other disability related organizations. Trainings will include an overview of symptoms of mental health and cognitive disabilities, effective strategies when working with people with a mental health or cognitive disability, and resources and services available to support them. The training will improve the ability of options counselors to provide appropriate, quality services to the people currently being served by DMH and others, including individuals in DMH-funded facilities and community programs as they prepare for discharge. Additionally, trainings will cover mental illnesses and behavioral issues commonly incurred by people as they grow older, such as anxiety, depression and dementia. An outside contractor will be engaged to provide the training around community geriatric mental health issues and cognitive disabilities, as well as to offer on-line opportunities for training in this area.

In order to better facilitate referrals and efficiency of communication between ADRC partner agencies, and to track service outcomes, Elder Affairs, after close consultation with MRC and the ADRCs, will purchase software which will allow ADRC partners to directly share information regarding consumers between their two IT systems. Referrals between ADRC partner agencies will be automated and eliminate the need for duplicate intakes, allowing for direct referral on the consumer's first phone call. One possible system to be explored is the ADRC Module of SAMS. This module is web-based, so it can be accessed by any agency with an internet connection and a password, facilitating quick roll out, and effortless addition of new agencies that join the ADRC networks. A task force made up of ADRC representatives will be created to review the ADRC module and other software options and develop a plan to achieve communication between the ADRC partner agencies. MRC is presently in the process of procuring a new database for the ILCs, which will include the capacity to import and export data to SAMS. Any new software obtained under this grant will be configured to maximize the integration/interface of data between systems.

During the second year of the grant, the Task Force will monitor delivery and impact of Options Counseling (see, "Continuous Quality Improvement and Evaluation," below), and will select two Work Group (see "Project Management," page 10) members to represent Massachusetts on a national task force, convened by the AoA, to develop a set of national Options Counseling standards.

Goals, Objectives and Subject Areas

The goal of this project is to strengthen statewide Options Counseling standards by improving the abilities of counselors to serve people with a variety of disabilities by realizing the following objectives:

Objective 1. Develop training to expand the ability of Options Counseling to serve people with disabilities including mental health and cognitive disabilities, and to ensure that all Options Counseling incorporates consumer direction, choice, self-determination and dignity of risk;

- Action 1. Work with DMH, MRC, ADRCs, Recovery Learning Communities, and agencies serving people with cognitive disabilities to develop and implement trainings for options counselors to better serve consumers with cognitive and mental health disabilities.
- Action 2. Identify statewide and local community-based agencies serving people with cognitive and mental health disabilities and develop strategies to reach out to them.
- Action 3. Work with ILCs and other ADRC partners to develop and implement consumer direction trainings.
- Action 4. Review statewide Options Counseling standards with all ADRC partners to determine need to include requirements for competency in serving consumers with a range of disabilities, including cognitive and mental health disabilities, and for education around consumer direction.

Objective 2. Research and acquire software, such as ADRC Module of SAMS, for all eleven ADRCs.

- Action 1. Establish task force to review appropriate software systems, choose most appropriate programs and interfaces, and identify necessary data sharing protocols with the ILCs' database system.
- Action 2. Install ADRC model software and adapt IT systems of ADRC partners to facilitate smooth operation.
- Action 3. Train all options counselors in use of chosen software.
- Action 4. Begin enhanced tracking of Options Counseling services enabled through new software.

Objective 3. Monitor delivery and impact of Options Counseling.

- Action 1. Assess and refine current evaluation procedure's effectiveness in gauging quality of service to people with mental health and cognitive disabilities

- Action 2. Develop, distribute and collect questionnaires from options counselors and other stakeholders about the process and benefits of implementing the new trainings.
- Action 3. Analyze evaluation and questionnaire results in order to prepare final report.

Objective 4. Work with AoA and other grantees to develop national Options Counseling standards.

- Action 1. Designate representatives to attend conference calls, in-person meetings and webinars to develop national Options Counseling standards.
- Action 2. Work with AoA technical assistance staff and other grantees on an informal and ongoing basis to develop national Options Counseling standards.

Target Populations and Geographic Area

In Massachusetts, Options Counseling is available to people age 60 or over, and to all adults with disabilities, regardless of income. Current standards for Options Counseling are being implemented at all eleven ADRCs. These standards will be reviewed with all ADRC partners to identify any changes needed to better serve people with disabilities including mental health and cognitive disabilities. Outreach activities in year 2 will be targeted toward reaching and more effectively serving identified populations.

There are 1.14 million people age 60 and over in Massachusetts, over 300,000 of whom have at least one disability. Over 1.3 million Massachusetts residents under the age of 60 have at least one disability. Nine percent of these need help with their personal care.² Approximately 500,000 adults in Massachusetts have a physical disability, 330,000 have a mental disability, and 225,000 have a sensory disability. Over 427,000 adults in Massachusetts are experiencing serious psychological distress.³ The Options Counseling program is only serving a fraction of this population. Within these populations, each ADRC identifies its own priority populations and target communities within their geographic areas.

Staffing Requirements

Current Options Counseling standards require ADRCs to 1) Identify one lead Options Counseling contact person to represent the ADRC; 2) Hire a minimum of two full time equivalents to be the primary options counselors

² Massachusetts Department of Public Health (<http://www.mass.gov/Eeohhs2/docs/dph/masschip/disability/disabilitymassstate.rtf>)

³ <http://www.oas.samhsa.gov/2k4State/MassachusettsMH.htm>

for the ADRC; and 3) Identify additional agency staff to be trained in Options Counseling. The Options Counseling lead, the designated options counselors, and other identified agency staff associated with the Options Counseling program must attend training sessions offered by Elder Affairs and MRC. The curriculum currently includes one day of core training, one ADRC agency cross-training, two additional electives to be completed within one year, and IT training for the purpose of reporting and monitoring Options Counseling activity. To date, all eleven ADRCs have identified an Options Counseling lead. Three ADRCs have identified the equivalent of two full time options counselors, and the rest are in the process of recruiting them. While most options counselors are case managers, nurses or social workers, there are no specific educational qualifications for Options Counselors in order to accommodate the differences in philosophy between the ILCs, which are built on a civil rights model, and the ASAPs, which are built on a medical model.

System Requirements

Standards of Administrative and Management.

Massachusetts currently has a set of program standards that guide and support delivery of Options Counseling.. These standards promote consistency across ADRCs and address the following areas: the elements of a session; the approach or orientation of the counselor, staffing and training requirements; outreach, and data collection and reporting. Protocols include an agreed upon definition of what constitutes an Options Counseling session, the inclusion of a 30 day follow-up for all consumers who receive the services, a set of shared definitions for the data elements being collected, including what constitutes a community and an institutional setting. Some agencies have developed additional written protocols based on these shared understandings.

Data and Information Systems.

This project proposes to enhance the ability of the ADRCs to track provision and outcomes of Options Counseling by acquiring a system that will automate sharing of service delivery information between ADRC partners. This new system will enable ADRC partners to transmit individual consumer information for referrals.

Partnership Requirement

In order to provide Options Counseling, ADRCs must sign agreements to adhere to the statewide standards (attached) developed by the state agencies and the three pilot sites. This provides a standardized approach across

the ADRC network, guaranteeing that the wide array of cultural and economic populations throughout the state receive the same quality product. Lead Options Counselors represent their ADRC at monthly meetings, in which they review best practices, training needs, outreach strategies, challenges, and overall direction.

Continuous Quality Improvement and Evaluation

A data system records Option Counseling consumers' stated goals and whether those goals are achieved. The consumer's type of living arrangement (nursing facility, community, etc.) at the onset and end of the counseling cycle is also recorded. These data include the number of counseling sessions that each consumer receives. Thirty days after the conclusion of Options Counseling, consumers are given an eight question consumer survey (attached), which is used to evaluate the quality of the service and helps identify diversions from nursing facilities. Semi-annually, options counselors report to the state their observations, including personal stories that show how the program is benefiting specific consumers.

This project will include an examination of these evaluation procedures and what changes could better track the impact of Options Counseling on people with disabilities. Additionally, acquisition of new software will enable Elder Affairs and MRC to better track services used and outcomes.

Organizational Capacity

Rachel Weiner, LPN, MA, Director of Options Counseling, has extensive experience working with seniors and people with disabilities, through program development, as a trainer, and as former director of a consumer hotline for elders. Now beginning its third year of operation, Massachusetts ADRC Options Counseling program serve 394 new consumers in the last six months. Of these, 53 percent of those stating their goal was to return home from a nursing facility were successful in meeting that goal. Fifty-eight percent of those living in the community and wishing to remain there were successful. Thirty-percent of those seeking admission to a nursing facility chose to remain at home after learning their full range of options.

Ruth Palombo, PhD, Assistant Secretary of Elder Affairs, is responsible for planning, policy development, quality monitoring and evaluation related to the Older Americans Act. Carole Malone, Director of Community Programs at Elder Affairs, oversees programs that include Options Counseling, the Councils on Aging Program, Serving Health Insurance Needs of Elders (Massachusetts' SHIP program) and Information and Referral. Elder

Affairs is the state unit on aging for Massachusetts. Since 2004, it has been implementing the state's "Community First" policy, an over-arching philosophy to empower elders and people with disabilities to live with dignity and independence in their communities, through access to consumer-directed supports and choices. Hallmark legislation in 2006 bolstered the Community First agenda by encouraging the state to work effectively with people with disabilities and elders to apprise them of the full range of long term care options. In October 2003, Massachusetts was awarded its first grant from the AoA and Centers for Medicare and Medicaid Services to develop ADRCs. Along with MRC, Elder Affairs administers the eleven ADRCs in Massachusetts and, under the direction of Ms. Malone and Ms. Weiner, has overseen the development of current statewide ADRC Options Counseling program, including the development of standards.

Ann Shor, Director of Independent Living and Assistive Technology at MRC, has over 30 years experience in the operation of consumer-directed services. MRC provides comprehensive services to people with disabilities that maximize their quality of life and economic self-sufficiency in the community. MRC oversees the state's vocational rehabilitation services, community living services, and disability eligibility determination, as well as Massachusetts' eleven ILCs, consumer-controlled agencies which connect people with disabilities throughout the state with services that include housing, transportation, personal care attendants, assistive technology and home modifications. A majority of staff and board members at ILCs have disabilities and are role models and mentors for people with often-complex health concerns. ILCs have championed the principal of consumer control and direction for over 30 years, and play a leading role in Options Counseling trainings.

Rosalie Edes, M.S., CAGS, Deputy Assistant Secretary, ODPP, has more than 30 years experience in disability program design and operations as well as public policy development and analysis. ODDP oversees disability-related services, rehabilitation, and employment support services through six administrative agencies. The Office provides disability policy, program, and financial planning leadership to prevention, intervention, individual and family support, housing, employment development, and long term care services across the Secretariat.

The Massachusetts Department of Mental Health is the state's mental health authority, providing access to services and supports to people with mental health disabilities of all ages, enabling them to live, work and participate in their communities. DMH will advise this project regarding extending Options Counseling to the people with mental

health and cognitive disabilities. It oversees one central, three area and twenty-six site offices throughout the state, which will be instrumental in developing and implementing training for options counselors surrounding mental health issues. DMH works closely with Elder Affairs, the other disability agencies, and its active and informed consumer and advocate community. In addition, DMH has senior level staff specifically dedicated to interagency planning and program development that are well versed on the ADRC initiative in Massachusetts.

Project Management and Stakeholder Participation

Elder Affairs will convene a Work Group, consisting of consumer and professional representatives from the ADRCs, the individuals described below, and a newly hired part-time Options Counseling Coordinator, who will support implementation of all grant activities.

Ruth Palombo will coordinate participation and contribution toward development of training and outreach from Elder Affairs and the aging service network, as well as across Secretariats and their respective regional networks of service agencies. Dr. Palombo will coordinate communication with AoA and oversee preparation of semi-annual reports.

Rachel Weiner will oversee all grant activities, including development of new trainings, monitoring of progress, and assuring communication with partner agencies. Ms. Weiner will supervise the new Options Counseling Coordinator.

Ann Shor, Director of Independent Living and Assistive Technology at MRC, will facilitate input from the ILC network into training and outreach surrounding the disability community through the Work Group.

Carole Malone will advise the development of training and refining of statewide Options Counseling standards.

Rosalie Edes will coordinate the involvement and contributions of the disability agencies within the Secretariat in the Options Counseling training and the standards development.